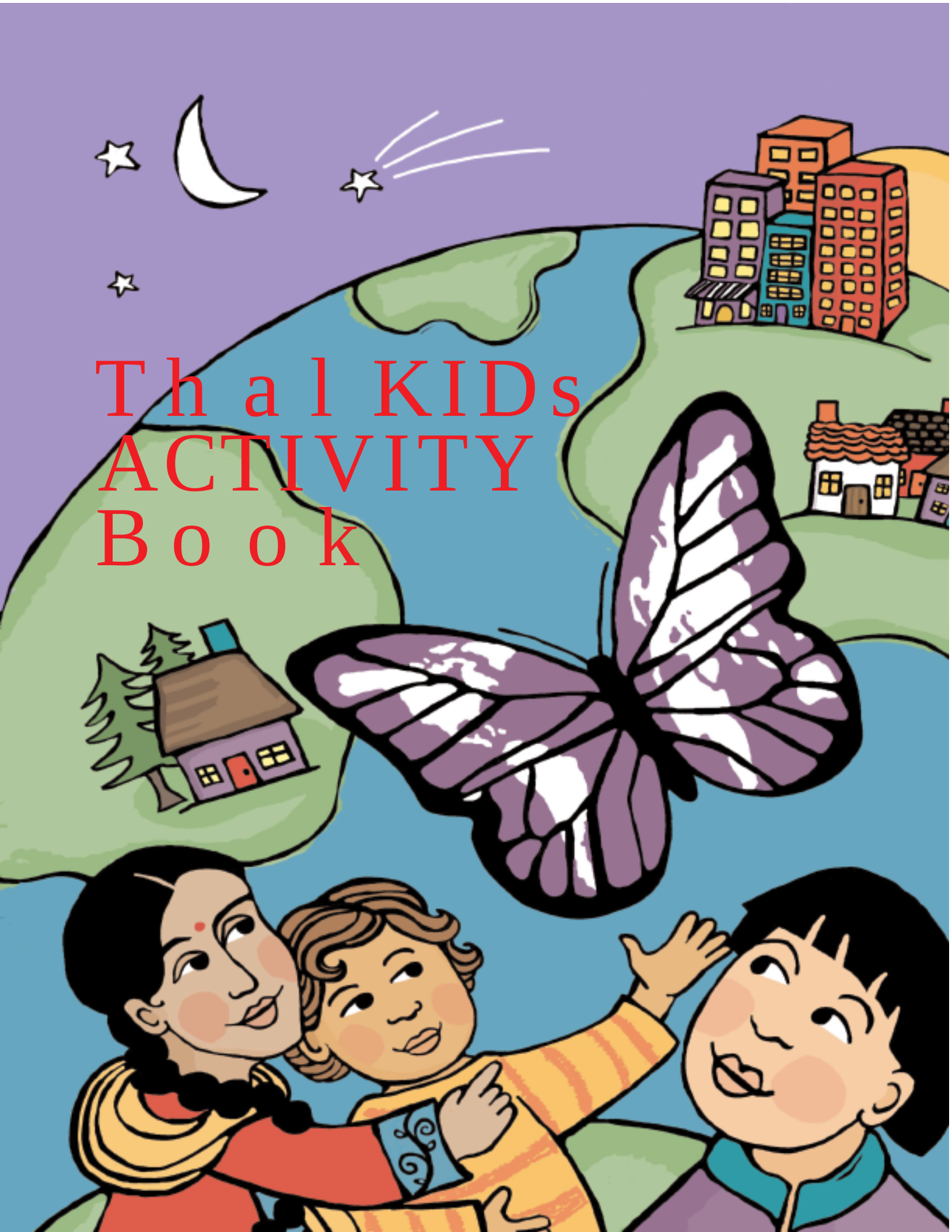




Th a l KID's ACTIVITY B o o k



Personal Record

My name is

My blood Type is

I live

My Doctor's Name is

My nurses are

I am yrs old

My brothers and sisters are

My pets names are

Notes to Readers

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What Happens with Thalassemia

Children born with thalassemia have red blood cells that are missing a protein called hemoglobin.



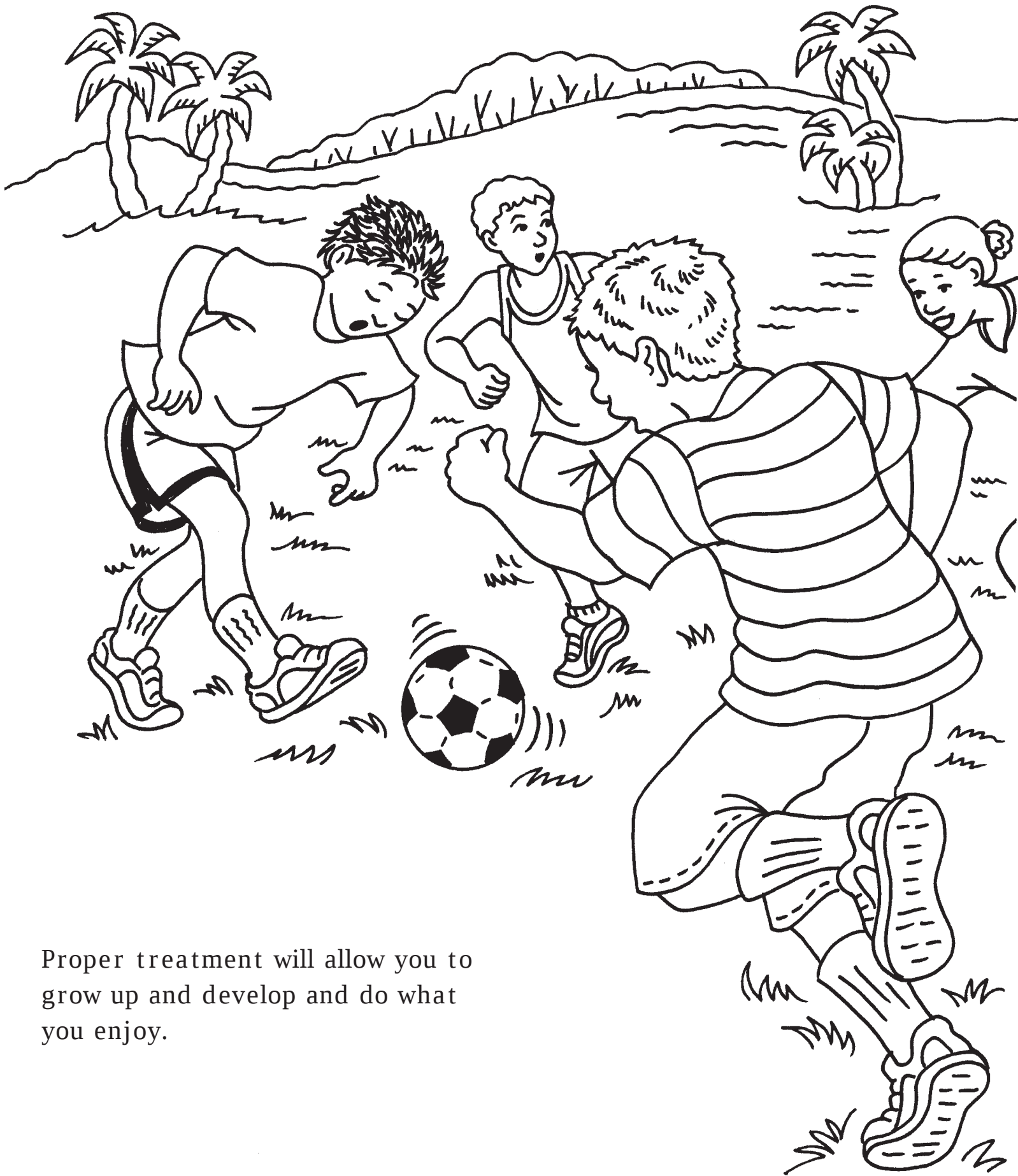
?

Hemoglobin is the part of your red blood cell that carries oxygen to your organs.



Blood transfusions will provide you with red blood cells that have plenty of oxygen. Blood transfusions also give you extra iron. This means you will have to work hard and follow your doctors advice about how to get rid of all of this “icky” iron.





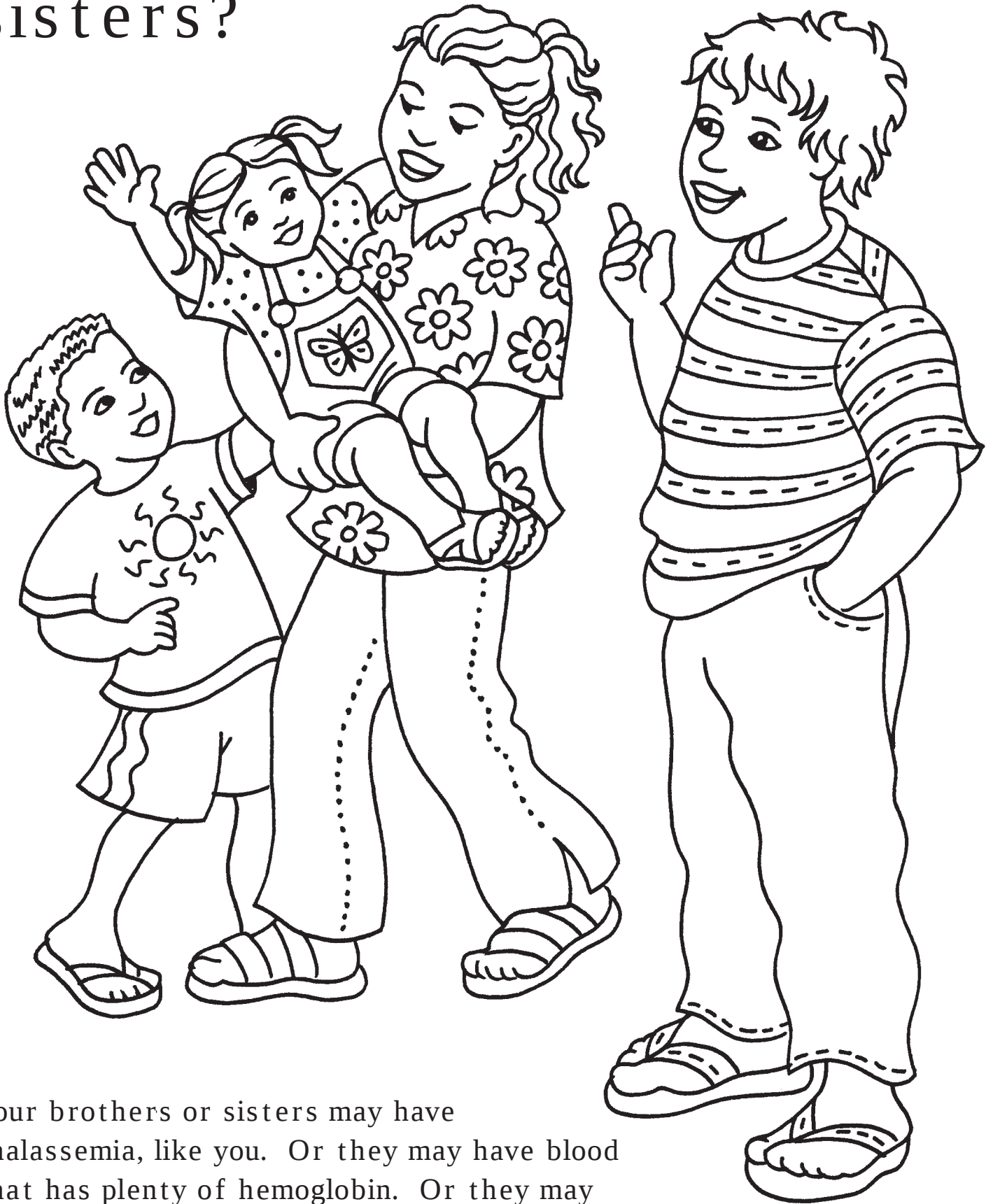
Proper treatment will allow you to grow up and develop and do what you enjoy.

How did I get thalassemia?



Thalassemia is something you are born with like the color of your eyes or hair. Having thalassemia is part of what makes you a unique and special person.

What about my brothers and sisters?



Your brothers or sisters may have thalassemia, like you. Or they may have blood that has plenty of hemoglobin. Or they may have something called thalassemia trait.

Who else has thalassemia?

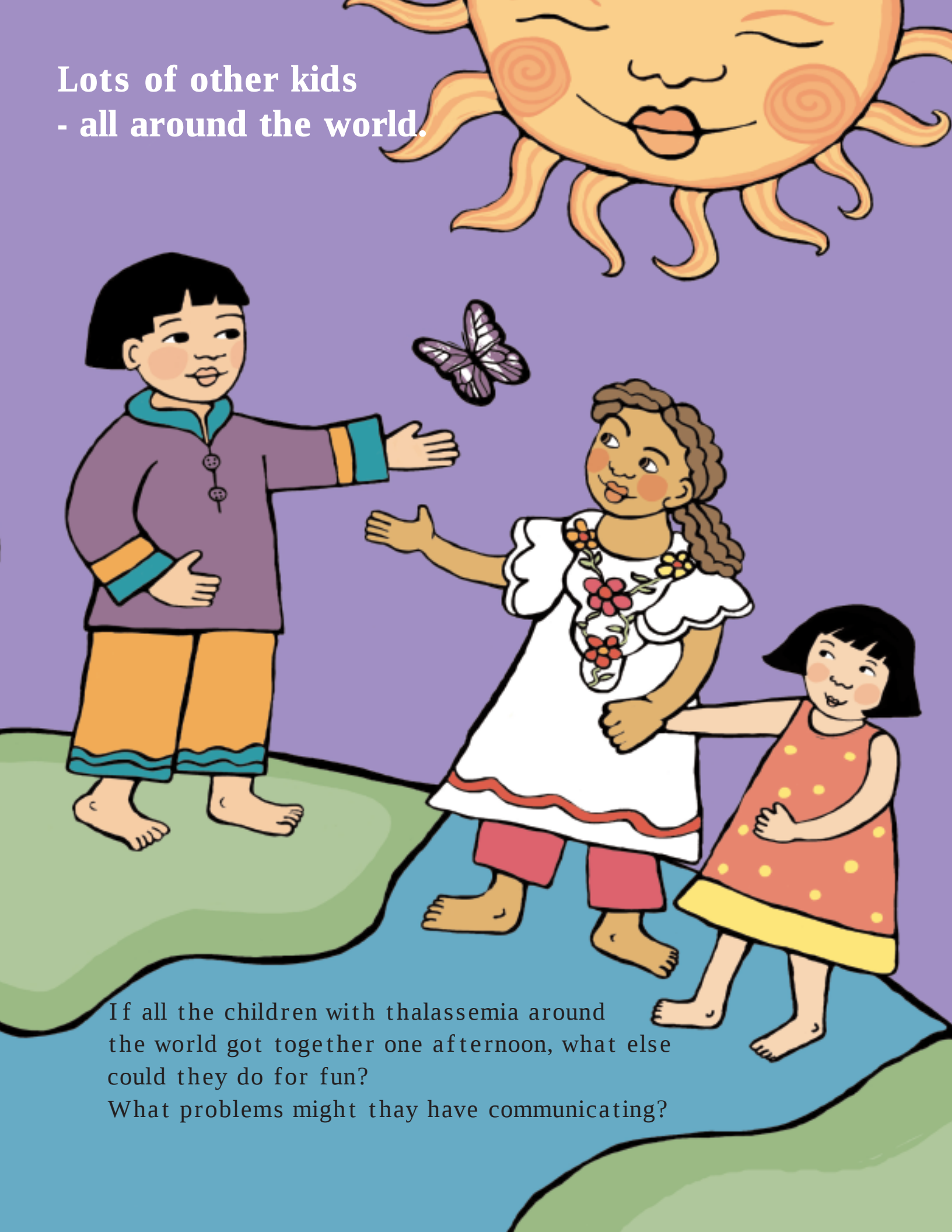


How do you think these kids lives are similar to yours?

How might they be different?

What are some things kids with thalassemia all around the world have in common?

Lots of other kids
- all around the world.



If all the children with thalassemia around
the world got together one afternoon, what else
could they do for fun?

What problems might they have communicating?

Science Class

Learning about Blood cells

Blood cells are made in the center of your bones, which is called bone marrow. Your bone marrow is a blood-making factory.

All blood cells come from one type of cell called a stem cell.

Stem cells grow and change into each of the special cells in your blood.

Young blood cells live in your bone marrow.

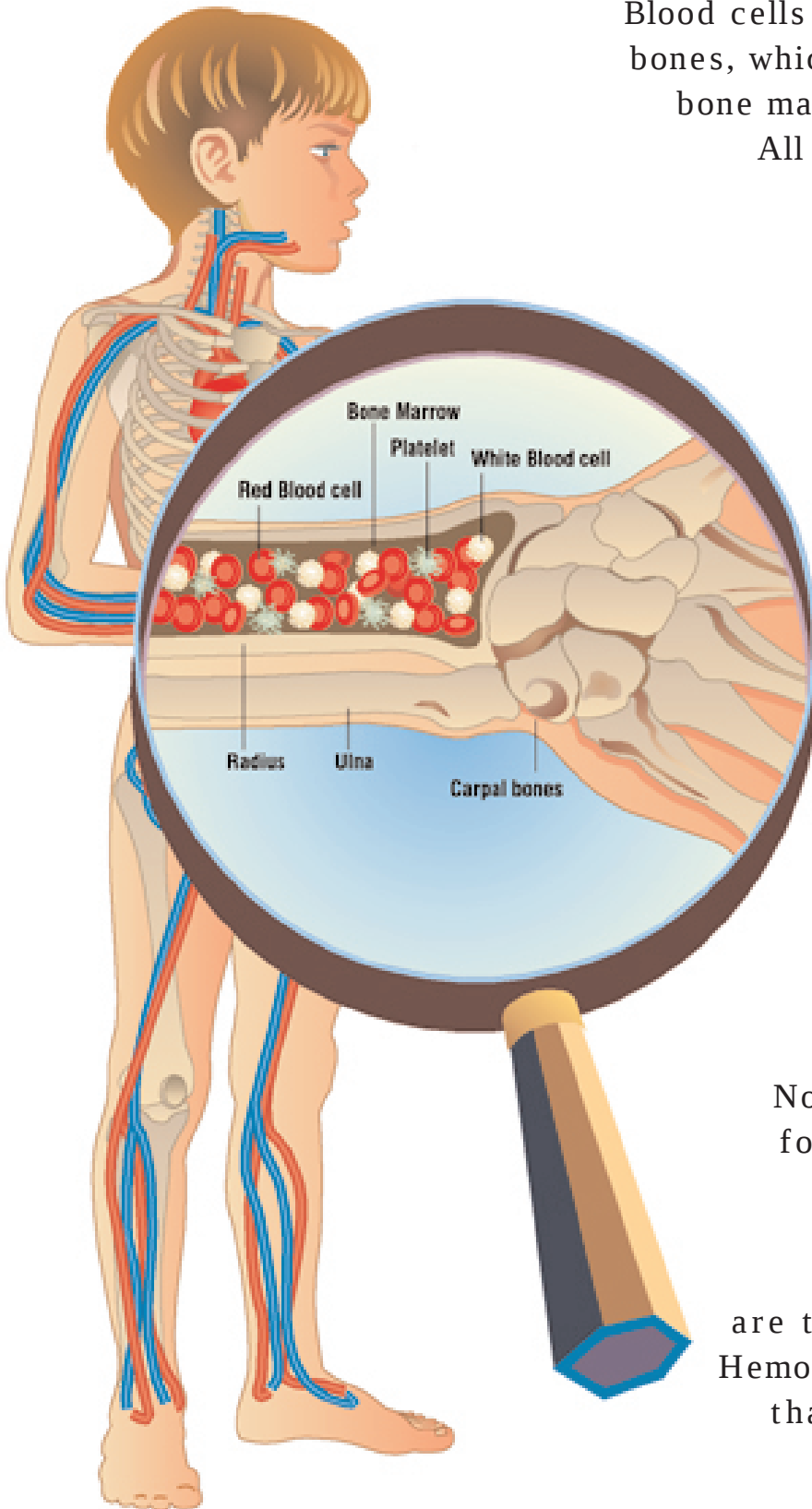
When they are full-grown they enter your blood and start working.

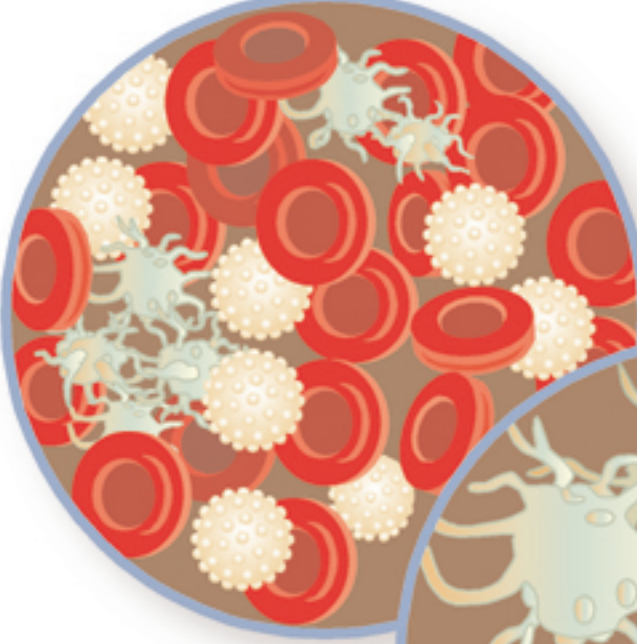
Red Blood cells carry oxygen to your cells.

People have over 30 trillion red cells in their body.

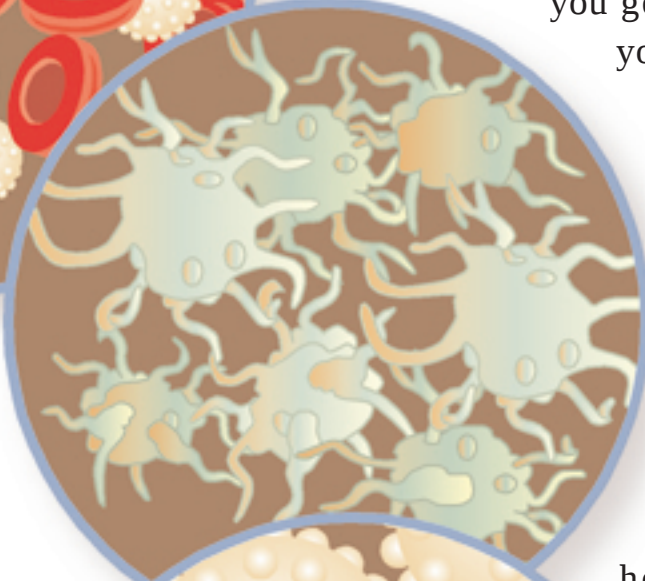
Normally each red blood cell lives for 120 days making 75,000 trips through your blood stream in its lifetime.

Inside red blood cells are tiny particles called hemoglobin. Hemoglobin is the part of your blood that provides oxygen to the body.

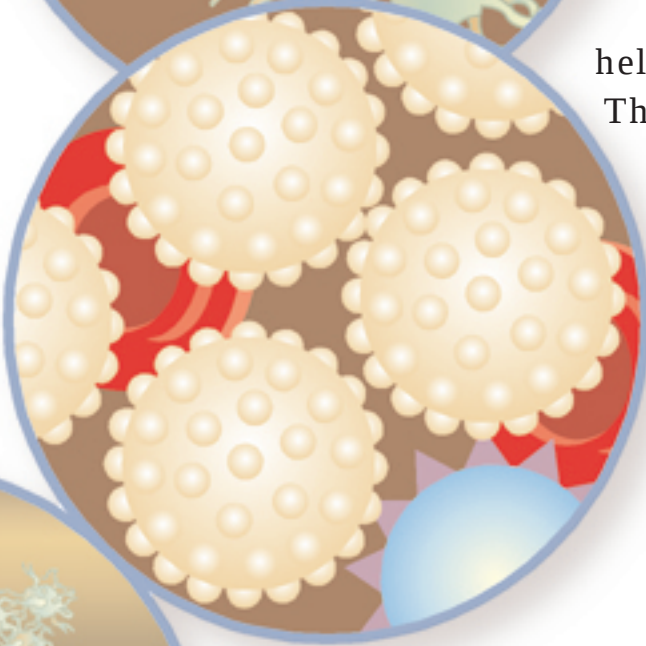




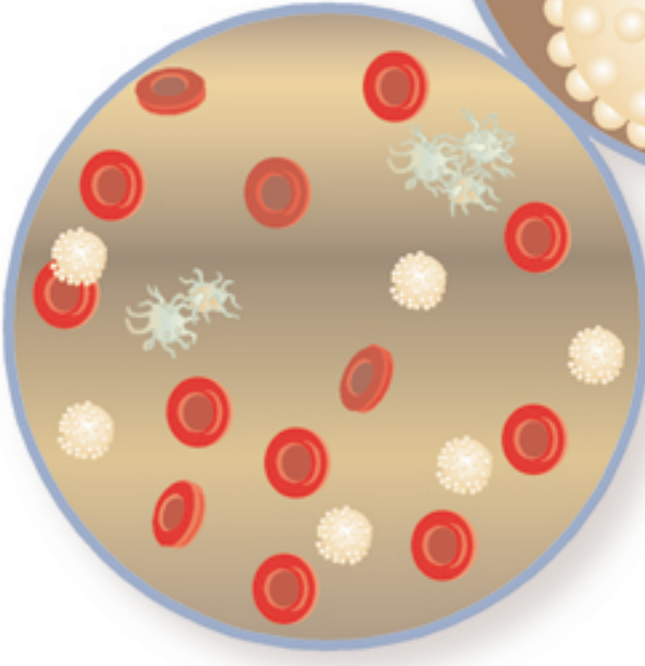
If you have thalassemia your red blood cells lack hemoglobin and you need some extra help. Lots of people pitch in to donate blood so that they can share their red blood cells with you. When you get a blood transfusion, you feel better because this blood has lots of hemoglobin which can carry oxygen to your cells.



Platelets are made of small pieces of another cell that also originated from a stem cell. They travel through your blood helping to form scabs over your cuts and control bleeding.



White blood cells help to fight infections. There are five kinds of white blood cells. Most patrol your body, hunting for invaders. When they find one, they attack and destroy the invader.

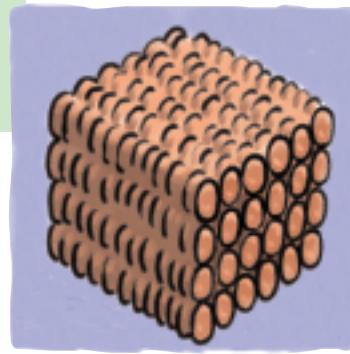


Plasma is the clear liquid part of your blood. It's over half of the stuff that makes up your blood. Plasma is 90% water. Plasma carries food energy to your cells and helps heal cuts and fight diseases.

Blood

Fun Facts

1.



Inside every cubic inch of your body are 80 million red blood cells.



2.

There are eight different blood types: A positive, A negative, B positive, B negative, AB positive, AB negative, O positive and O negative. O positive is the most common and AB negative is the rarest blood type.

3.

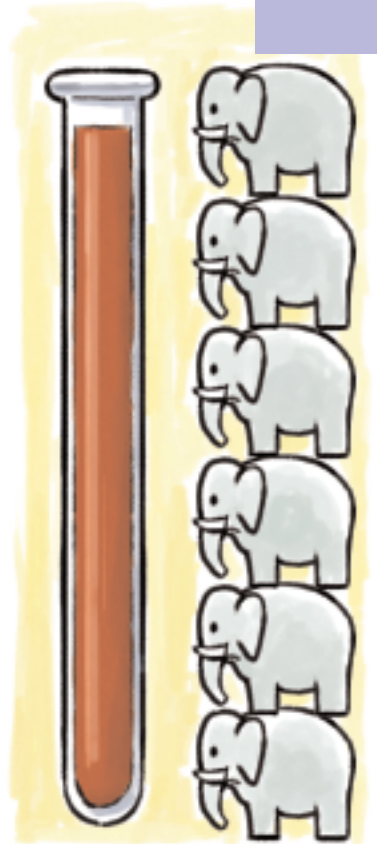
Your body has 70,000 miles of blood vessels. They could stretch around the earth over 2 1/2 times.



4.

Your heart pumps over 40 tons of blood a day, more than the weight of 6 full-grown elephants! That adds up to over 75,000 pints of blood in a single day.

check!



5.



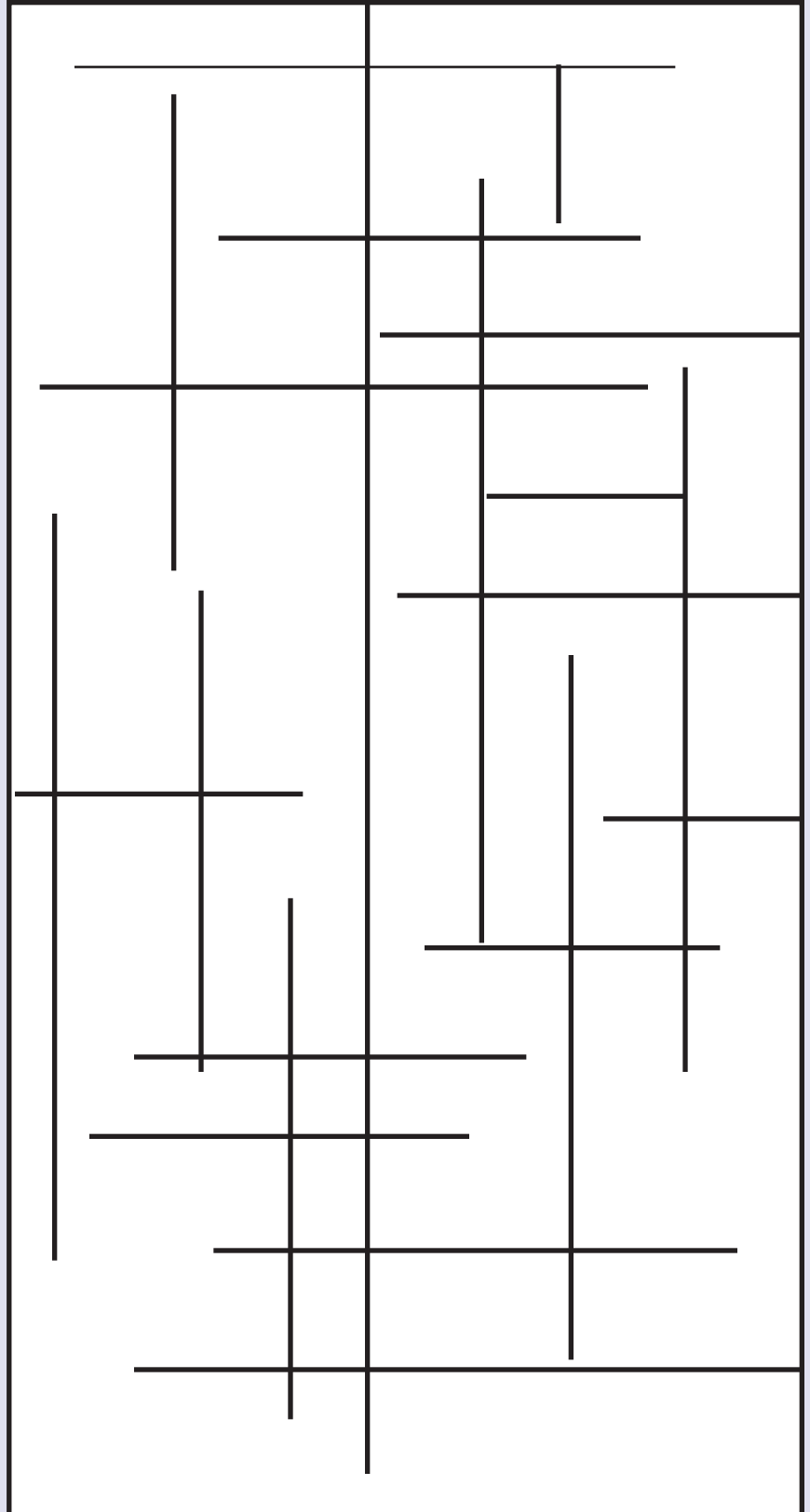
As an adult you have about 5 liters of blood. That is more than two big soda pop bottles.

Run a race with your Blood.

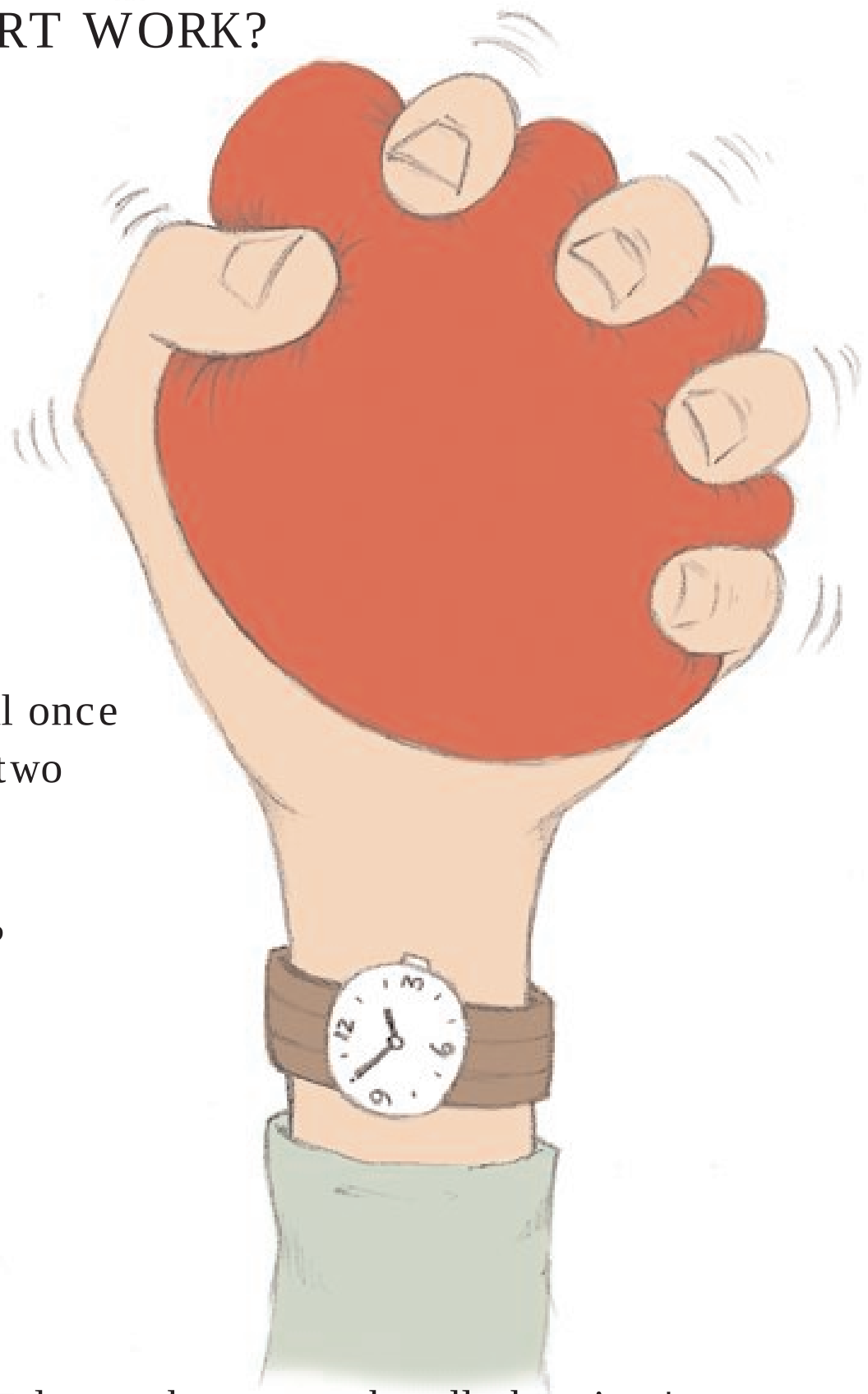
(Connect the dots or illustrate with a maze)

This race will only last 45 seconds so get ready!

1. Blood moves out of your heart and rushes to your lungs.
2. In your lungs, red blood cells load up on oxygen and run back to your heart
3. Blood gets a big push out of your heart and into arteries
4. Your blood races around your intestines. It pauses to pick up food energy. The blood then heads to the liver.
5. In the liver, food energy is repackaged for the body to use. Your blood picks up the newly packaged food energy and delivers it to your cells.
6. Blood speeds energy and oxygen to every cell in your body. Your blood picks up waste products made by your cells.
7. Your blood zooms though your kidneys. They filter and clean your blood.
8. Blood returns to your heart and then rushes back to your lungs where carbon dioxide is dumped off.



HOW HARD DOES YOUR HEART WORK?



Squeeze a ball once
a second for two
minutes.

Can you do it?

Guess What?

That's how hard your heart works all the time!

You be the Doctor

Count your heart rate.
Use a watch with a second hand.
Press gently on a pulse point.
(illustrate pulse points).
You should feel a soft beat.

Count the number of beats
in 15 seconds.

Multiply by 4.

This number represents
the total beats per minute
or heart rate.

Compare heart rates of friends,
family and pets.

What do you find?

What is your heart rate
in the morning,
after you eat,
exercise
or study?





Tell me more about Blood
Transfusions

Your are an extra special kid because you get billions of new red blood cells every time you have a transfusion. Your doctor will most likely want to keep your haemoglobin level above 9.5 – 10 g/dl and may recommend transfusions every 2-4 weeks.

This new blood has lots and lots of iron that needs to leave your body as soon as possible. How much iron? Each new red blood cell has almost one billion atoms of iron. WOW! That is a lot. It is a good idea to keep a record of your blood transfusions so you can keep track of how much iron you need to get rid of.

Remember to work hard at chelating iron.

Just follow your doctor's advice about the best way for you to make the iron disappear and stick to the plan. Wow – now that is super cool!

WOW – now that is super cool!

Zooma's Adventure

Not so far away lives a little butterfly named Zooma. Zooma has graceful orange wings and a fuzzy brown body.

She loves to soar and swoop from flower to flower and to feel the warmth of the sun as she glides through the sky.

Zooma flew pretty fast. But there were other butterflies who flew much, much faster than she.

Every day Zooma roamed around and watched the butterflies across the meadow, taking nectar from some lovely purple flowers.

Zooma refused to take the nectar. Still, she hurried across the meadow, hoping she could join the others in whatever game they might play after they finished with the nectar.

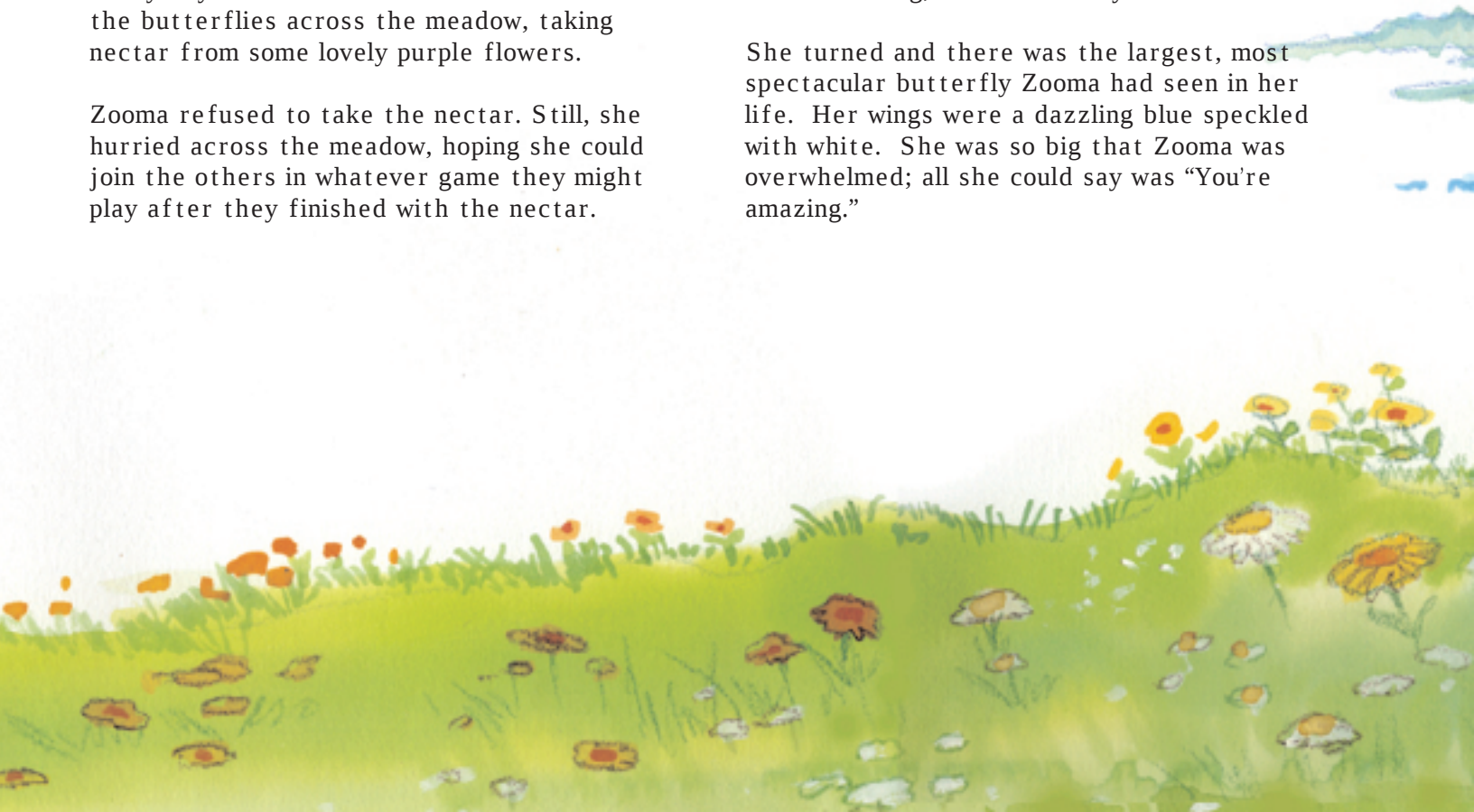
But before Zooma caught up with the other butterflies they took flight, chasing and playing with one another.

"Oh, wait!" Zooma cried. "Wait for me! Please!" But the other butterflies were already too far away.

Zooma started to cry. "It just isn't fair!" she thought as she landed on a leaf.

Suddenly, Zooma heard a voice behind her. "What's wrong, little butterfly?" it asked.

She turned and there was the largest, most spectacular butterfly Zooma had seen in her life. Her wings were a dazzling blue speckled with white. She was so big that Zooma was overwhelmed; all she could say was "You're amazing."



"Thank you," said the immense butterfly. "My name is Shayera. Now why don't you tell me what is wrong."

And so Zooma told Shayera how she wished that she could fly as fast as the other butterflies.

"Well," said Shayera, "if that's what you want, the answer is simple, 'you must take all of the nectar in this flower,'" Shayera said.

"But I can't!" Zooma said. "I dislike nectar!"

Shayera answered gently, "if you want to be fast, you must take it all – and take it every day."

Zooma took a deep breath and took a taste forcing herself to swallow. Then she took some more, and some more, until finally she had taken all the nectar in the flower.

"I'm done!" she said. "I can't wait to fly now!"

"Wait," Shayera said. "First, listen to me Zooma. You're not going to be any faster yet."

"But why? "

"You have to take it every day. If you do you'll start to get a little faster and a little faster, until one day you'll be just as fast as all the other butterflies."





“Great!” Zooma said. “And then I can stop taking the nectar!”

“No, not if you want to stay fast. If you stop taking it, little by little you’ll lose all the speed you gained.”

Everyday Zooma took her nectar and everyday Shayera was there to keep encouraging her.

One day Zooma noticed that it was easier for her to keep up with Shayera when they were flying across the meadow and soaring into the glorious flower patch. That made her very happy, and she took the nectar without complaining that day.

On another day, Zooma was sitting on a tree branch enjoying the shade when she saw a brown butterfly land on a bush some distance away.

The brown butterfly did not notice the ferocious cat crouched over and ready to jump up and catch the butterfly. Zooma acted quickly.

“Fly away!” Zooma yelled, but the brown butterfly didn’t hear her.

Quick as a flash, Zooma jumped off her branch and zoomed toward the other butterfly. She flew right into her and knocked her away just as the cat sprang up to catch her.

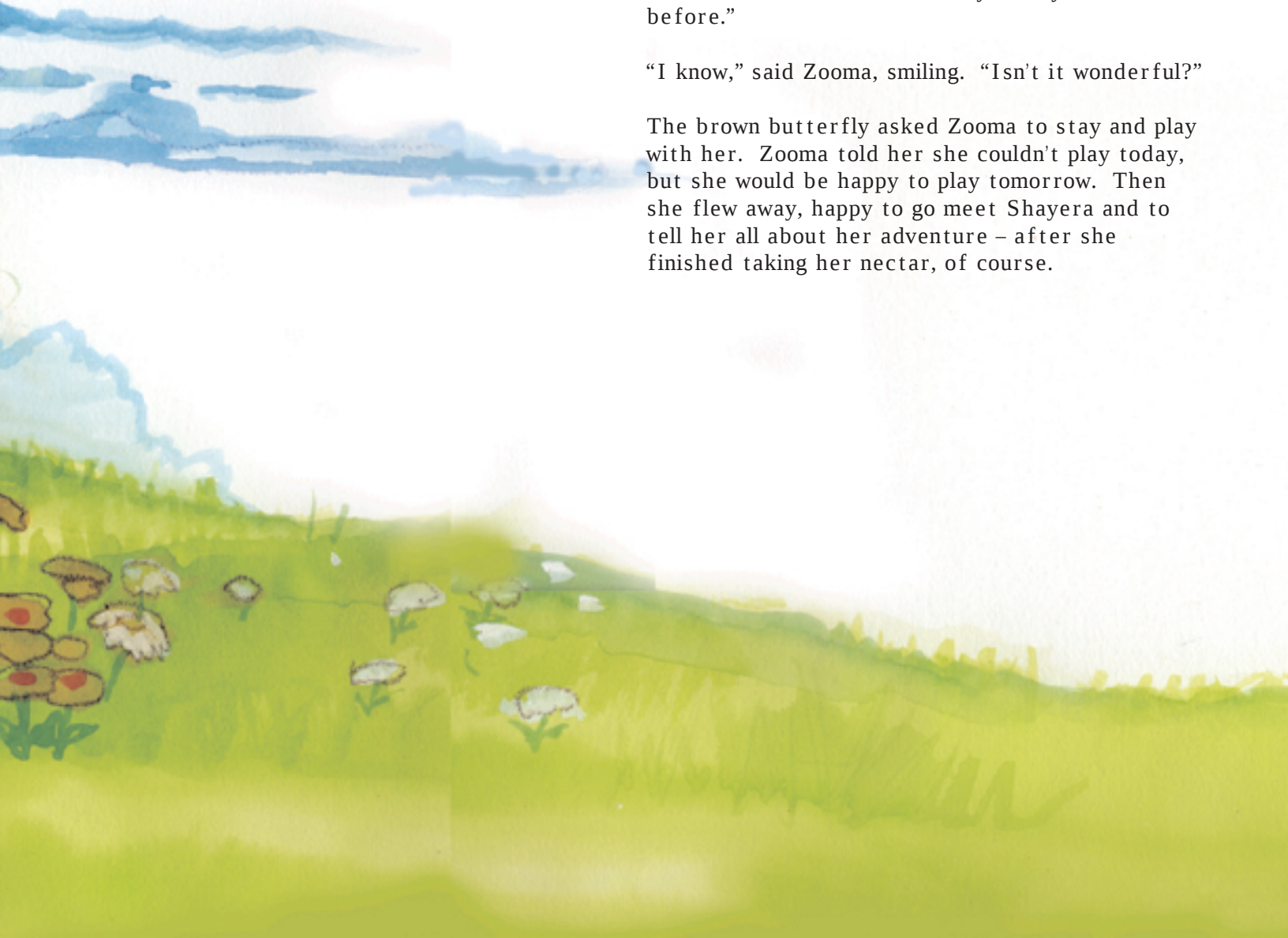
“Yow!” the brown butterfly cried as she flew away with Zooma. “You saved my life. Thank you.”

“You’re welcome,” Zooma said, blushing but feeling very proud.

“I can’t believe you did that,” the brown butterfly continued. “I’ve never seen anyone fly that fast before.”

“I know,” said Zooma, smiling. “Isn’t it wonderful?”

The brown butterfly asked Zooma to stay and play with her. Zooma told her she couldn’t play today, but she would be happy to play tomorrow. Then she flew away, happy to go meet Shayera and to tell her all about her adventure – after she finished taking her nectar, of course.





OUR IRON DETECTORS
ARE PICKING UP HIGH LEVELS
BELOW... FE MAN
MUST BE IN THE AREA.

LET'S CHECK THIS OUT.

IRON AVENGERS



WE'RE HERE
TO HELP YOU BATTLE
FE MAN !!!





Meet Some Real Life Iron Avengers



Michael lives in England. He is married and works as a computer networking expert. Michael is President of the United Kingdom Thalassaemia Association and is a Board Member of the Thalassaemia International Federation.

Michael is a true Iron Avengers working hard to teach other patients about the importance of chelation and sticking to your compliance plan.



Merula was born in 1966. She lives in San Paolo, Brazil. Merula is married to Dennis and they have three children, Danielle (10), Dina (6) and Roberto (4). Merula is very compliant with her treatment and works hard to help other children in her country. She is President of the Brazilian Association of Thalassaemia "ABRASTA".

Merula also runs a successful importing and exporting business. In her free time she travels the world to further improve the care and treatment of thalassaemia.

Merula's advice to you is:
"Never lose the trust that you can accomplish anything you wish. Impossible is nothing."

To meet other Iron Avengers check out www.thalkids.com



Are You an Iron Avenger?



Tell us why you are a superhero when it comes to tacking care of yourself! We want to learn more about you! Submit a story or a picture or a poem about yourself. Tell us about special customs and traditions where you live and all about your favorite holiday or sport or best friend. Tell us whatever you want! Each entry will be considered for publication in a book or calendar that will be shared with other special kids just like you – with thalassemia. All contributions submitted will be considered for posting on ThalKids.com.

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More Tests?



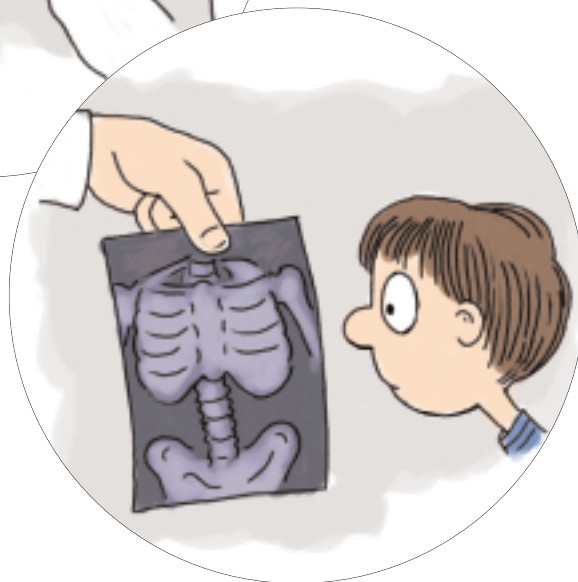
Now you know the way to stay healthy is getting new blood and getting rid of iron from the transfusions. But just to make sure that everything is going as planned and to make sure that you are healthy your doctor may give you extra tests.



It is smart to ask your doctor or nurse about these tests so that you can learn even more about how to stay well.



Here are some questions you can ask.



Pop Quiz

An atom is

- a) a piece of candy
- b) an earthworm
- c) a tiny particle

There are nearly _____ atoms of iron in a red blood cell.

- a) 20 b) 1,000 c) 1,000,000,000

What should I do to get rid of this iron?

- a) Stay encouraged
- b) Follow your doctors plan
- c) Never give Up
- d) All of the above

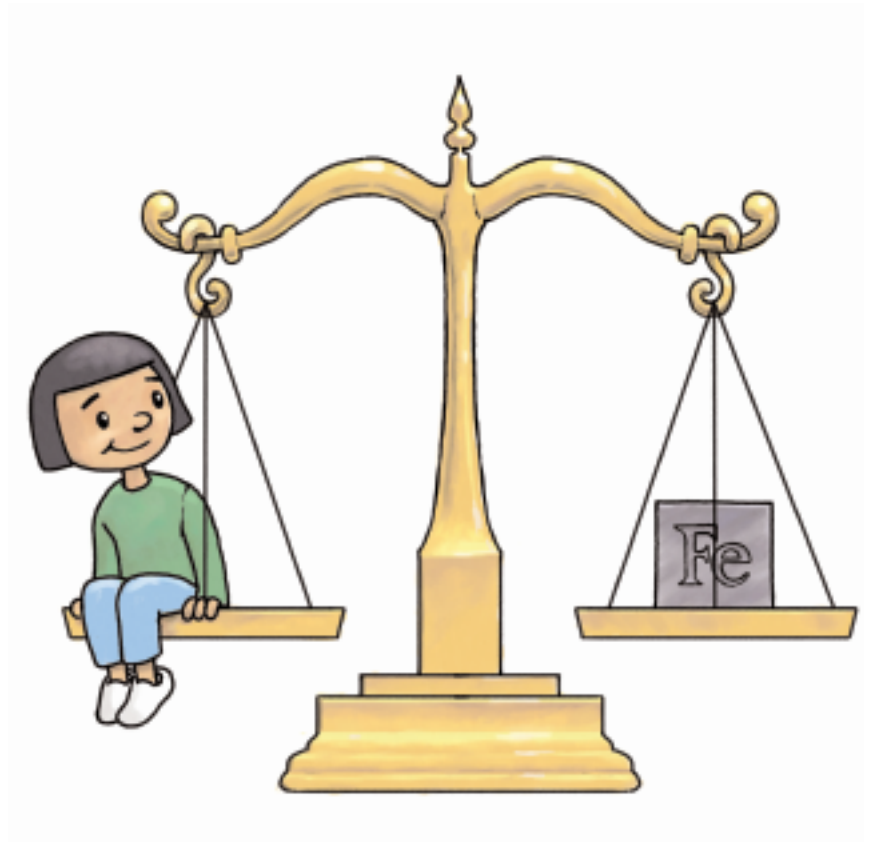
True or False -

- Your kidneys filter and clean your blood.
- The first stop for your blood once it leaves the heart is the liver.
- Every day your heart pumps over 75,000 pints of blood.

Fill in the blank

_____ Blood Cells help to fight infections.

All blood cells come from _____.



Hemoglobin is the part of your _____ blood cell that carries oxygen to your organs.

Every day Zooma and Shayera take their _____.

FE is the chemical symbol for -

- a) water
- b) plastic
- c) iron
- d) gold

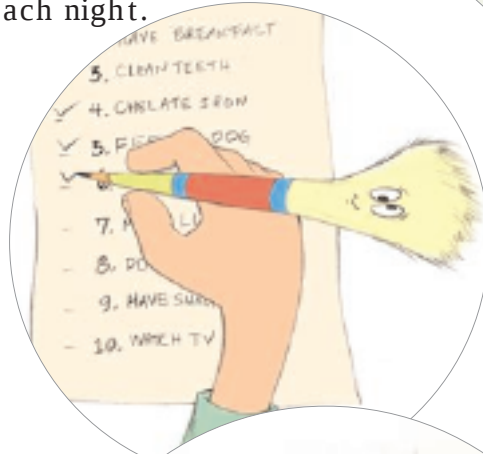
Chart your success!

Keeping a Journal It is easy to forget some things. Like doing your chores or finishing your homework. But it is easy to remember fun things like calling our friends and finding time to play or sing a song. Kids with thalassemia have lots of extra things to remember. It is important that you remember to take care of yourself, exercise, eat well and follow your doctor's advice especially about chelating iron.

Here are some ideas to help make taking care of yourself fun:

Make a List

- Make a list each morning and cross off all the things you accomplished each night.



Reward Yourself

-with a treat each time you finish your medicine.

This treat could be – an extra long playtime or sleeping in on non school days or an extra serving of dessert.

Take a friend with you to the doctor.



Make a Calendar - to keep track of all your visits to the doctor. Decorate the calendar with pictures and stickers.

Make a Card- to thank your nurse or doctor for taking care of you – it will brighten their day.

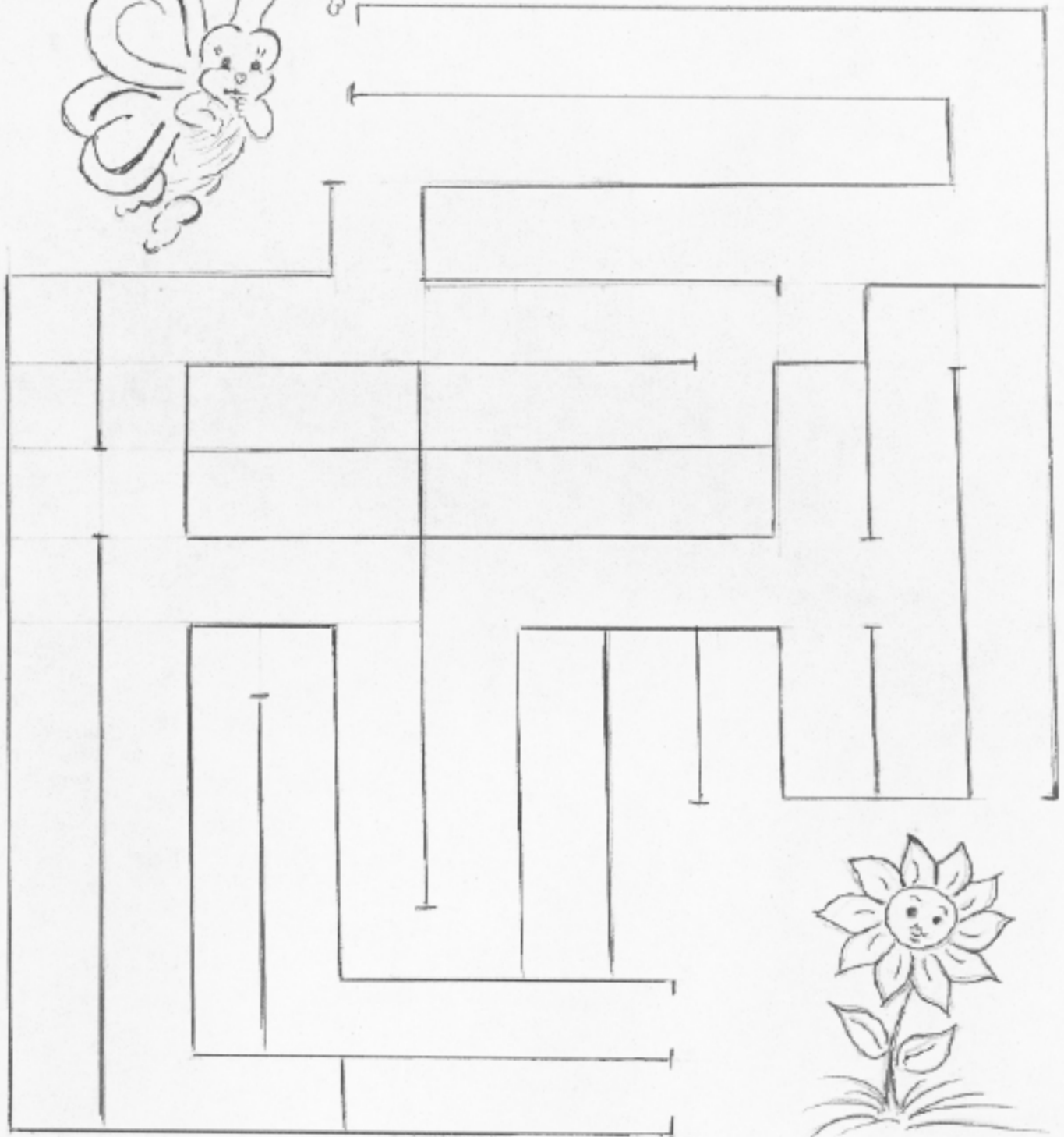


Connect the Dots

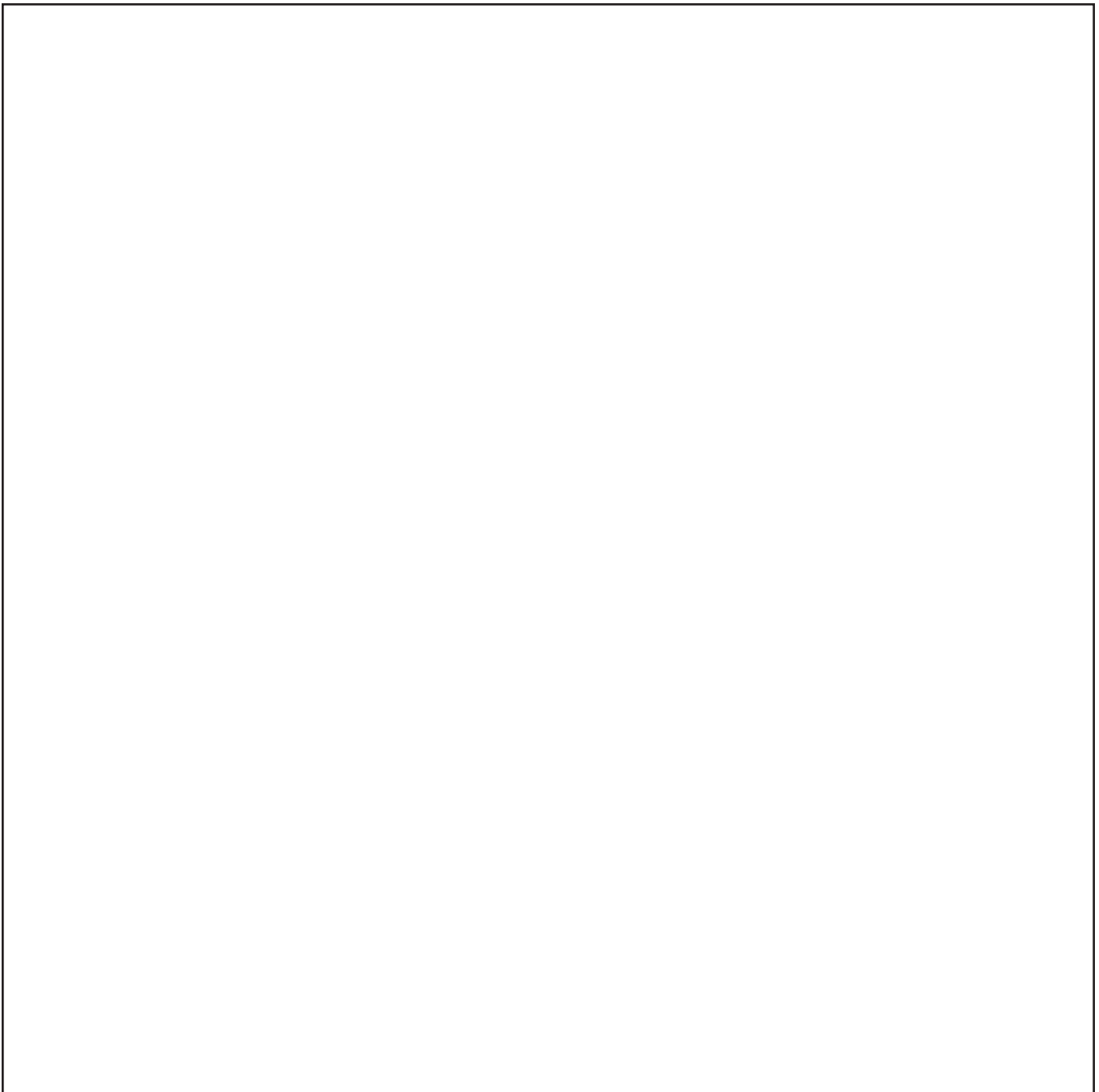
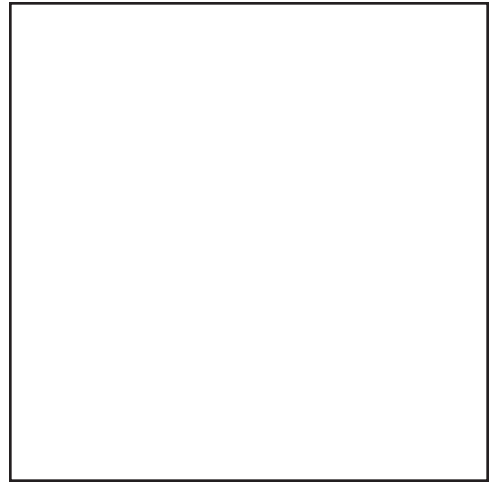


Maze

Lets help the little butterfly find a beautiful flower.



Draw this



Your own Pages U 0 g

N

b

Z

o

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J

for old and new friends ...

d

!

G

R

Z

S

7 a % 2) v \$



D

(

X

to write a note or leave an autograph.

b

m 0 / c Y -